

Consent Form

IRB approved on: 01/17/2012

Expires on: 01/16/2013



DEPARTMENT OF SPECIAL EDUCATION
THE UNIVERSITY OF TEXAS AT AUSTIN

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IRB PROTOCOL #2011-12-0038 Informed Consent to Participate in Research (Transition Focus Groups)

The University of Texas at Austin

Title: Family Support Issues across the lifespan in Families of Children with Autism and other Developmental Disabilities

Introduction:

The purpose of this form is to provide you information that may affect your decision as to whether or not to participate in this research study. The person performing the research will answer any of your questions. Read the information below and ask any questions you might have before deciding whether or not to take part. If you decide to be involved in this study, this form will be used to record your consent.

Conducted by

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Purpose of the Study:

You are being asked to participate in a focus group research study about supporting families and professionals in the transition process. The purpose of this study is to understand how parents of the youth with disabilities, including those from culturally and linguistically diverse backgrounds, perceive school-family collaborations/partnerships in planning their child's transition to adulthood life. We are also interested in your perceptions regarding your support needs across a variety of areas (e.g., education, communication, instruction, behavior, social, and vocational) in planning for your son or daughter's transition. We will use this pilot data to add to the research base on supporting families during the transition process and as pilot data for a grant proposal on improving transition outcomes.

What you will be asked to do:

- Participate in a discussion with other parents of children with disabilities or in individual interviews about your partnerships with professionals in planning your child's transition
- Answer questions in a group setting or individual interviews about the services and supports your family or your child receives
- You may be allowed to participate in the focus group or individual interview via phone or Skype, if needed.

PI UT EID: nz839

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- Focus group discussions will be audio or video taped to allow for professional transcription.
- Participate in a follow-up focus groups or interview to clarify findings and/or review the summary of findings for accuracy and completeness.

Total estimated time to participate in study is 1½ hours – 2 hours.

What are the risks involved in this study?

- These procedures may involve risks that are currently unforeseeable; however, the risks are minimal and are no greater than everyday life.
- For this study, data will be collected on the participant's opinions. It is possible that these data could become known to others, which would be a breach of confidentiality. To minimize the risk of a breach, all the paper data will be kept in a locked file cabinet in an office (Room 532F) at the University of Texas. The video and audio data will be stored on the secure UT server managed by the university. For transcription purposes, the video and/or audio files will be shared with a professional transcription to transcribe the data. To protect confidentiality, this person will keep confidential all information transcribed and will erase all files after successful transcription of the data. Additionally, all names and identifying information will be removed and changed prior to dissemination of the results in any resulting publications or presentations. The data will retained in Sanchez Hall, Room 532F in a locked file cabinet for a period of 5 years and will then be destroyed.
- The confidentiality of your comments may be compromised. While all participants will sign an agreement stating intent not to repeat the information disclosed by others, it is possible someone will share the information with people outside the research group.

What are the possible benefits of this study?

- The results of this research may provide information to help your family understand the components leading to improved family supports for your family and/or your child.
- You may learn from other participants new strategies for meeting your family's support needs or the support needs of the person with a disability in your family.
- You may develop a sense of community through participation in a discussion with other families with children with disabilities.

Do you have to participate?

No, your participation is voluntary. You may decide not to participate at all or, if you start the study, you may withdraw at any time. Withdrawal or refusing to participate will not affect your relationship with The University of Texas at Austin, Texas Parent to Parent, Autism Society of Greater Austin, or Partners Resource Network in anyway.

If you would like to participate, you may simply sign this form.

Will there be any compensation?

- There is no compensation for being in the study
- Participation in this study will not cost you anything.

What are my confidentiality or privacy protections when participating in this research study?

- Authorized persons from The University of Texas at Austin and the Institutional Review Board have the legal right to review your research records and will protect the

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confidentiality of those records to the extent permitted by law. If the research project is sponsored then the sponsor also has the legal right to review your research records. Otherwise, your research records will not be released without your consent unless required by law or a court order. While confidentiality is adhered to in the highest manner, there are a few instances when confidentiality may be broken. These instances include: criminal activity, child neglect, child/elder abuse, or an indication of clear, serious, and direct harm to self or others. To protect those affected, these instances will be reported to the police, Child Protective Services, school counselor, or other appropriate authority.

Video-recorded/audio-recorded data:

- Sessions will be video and/or audio taped, unless you state otherwise when signing this consent.
- Audio and/or video tapes will be transcribed; the transcriptionist has her own secure website for uploading audio/video. She erases all tapes once transcription has been completed.
- Video/audio recordings will be kept on the secure UT WebSpace server (password protected and approved by the university for storage of the highest security of data, Category I level data); until the videos have been successfully uploaded, they will also be kept locked in the Sanchez office in room 532F
- You may allow for the video tapes to be used for educational purposes and for research dissemination (e.g., at conferences or during class instruction). Only researchers will be authorized to show/use these videos for conference presentations or class instruction.
- Video clips of portions of the sessions may be kept for up to 5 years if used for instructional purposes.

Other data:

- Data will be coded so that no personally identifying information is visible on them.
- Data will be kept secure in a locked office (SZB 532F).
- Data will be viewed only by authorized investigators at the University of Texas who are directly involved in the research.
- For the purpose of future analysis, transcript data will be kept for a period of five years.
- Video clips of portions of the sessions may be kept longer than 5 years if used for instructional purposes.
- If the results of this research are published or presented at scientific meetings, your identity will not be disclosed.
- The data resulting from your participation may be made available to other researchers in the future for research purposes not detailed within this consent form. In these cases, the data will contain no identifying information that could associate you with it, or with your participation in any study.

Whom to contact with questions about the study?

- Prior, during, or after your participation, you may contact the researcher (Nina Zuna, 512-475-6580) or send an email to nzuna@austin.utexas.edu. This study has been approved by The University Institutional Review board and the Study Number is 2011-12-0038.
- You are free to withdraw your consent and stop participation in this research study at any time without penalty or loss of benefits for which you may be entitled.

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- Throughout the study, the researchers will notify you of new information that may become available and that might affect your decision to remain in the study.

Whom to contact with questions concerning your rights as a research participant?

For questions about your rights or any dissatisfaction with any part of this study, you can contact, anonymously if you wish, the Institutional Review Board by phone at (512) 471-8871 or email at orsc@uts.cc.utexas.edu.

Participation

If you would like to participate, you may simply sign this form and return to the researcher who is facilitating the focus group. You will receive a copy of this form.

Signature

You have been informed about this study’s purpose, procedures, possible benefits and risks, and you have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time. You voluntarily agree to participate in this study. By signing below, I also agree not to share what was discussed in the focus group with others

I have read the above information and have sufficient information to make a decision about participating in this study. I consent to participate in the study.

Participant Signature Date: _____

Signature of Person Obtaining Consent Date: _____

Signature of Investigator Date: _____

Video/audio taping. Sessions for this project will be videotaped or audio taped. The purpose for the video and audio taping is to allow for a professional transcriber to type the notes from our discussion. This is an important component in qualitative research. Your check below indicates your permission for video/audio tape use. **Please check ONE option below.**

Yes, I give my permission for video and audio tape from this research study to be used for data analysis and educational purposes (e.g. shown at conferences or classes for purposes of instruction or research dissemination).

OR

Yes, I give my permission for video and audio tape from this research study to be used for data analysis ONLY (e.g., only researchers and research students will view the video tapes).

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OR

Yes, I give my permission for ONLY audio taping of this research to be used for data analysis (e.g., only the transcriber, researcher, and students will have access to the audio and transcribed records).

No, I DO NOT give my permission for any videotaping or audio taping.